

Social Security Administration
Compassionate Allowance Outreach Hearing on Cancers
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On behalf of Dana-Farber Cancer Institute, an NCI-designated comprehensive cancer center located in Boston, Massachusetts, thank you for inviting me to testify at today's hearing on compassionate allowance guidelines. We are pleased that the agency is planning to make changes to accelerate the approval of benefits for certain children and adults with cancer.

Approximately 1.4 million cases of cancer are expected to be diagnosed in 2008, and 565,650 Americans are expected to die of cancer this year. The Institute of Medicine and the American Cancer Society, among others, have recently issued seminal reports that document the range of medical and psychological issues faced by individuals and families with cancer. These reports also examined the financial crisis that has become a primary issue for so many cancer patients. While receiving active therapy, a significant number of cancer patients are uninsured or underinsured and/or may be subject to large co-payments and insurance lifetime and annual caps. Coupled with an inability to perform work given the disabling impact of their disease, the financial impacts to these patients and their families are enormous.

Medical and Functional Criteria. Due to the heterogeneity of cancer, a combination of one or more variables will need to be considered in making a determination for disability benefits. Depending on the stage at diagnosis and the underlying health of the patient, there are certain cancers where clinical oncologists can now predict with a high degree of probability that the disease will have a long term disabling consequences. While most cancer patients, especially younger patients who are in relatively good health, will achieve a near normal recovery and will strive to maintain their employment and regular routine, older patients and patients with advanced disease tend to be at greater risk of

permanent toxicities, particularly if they have underlying medical conditions that affect their performance status.

The variables to consider in this equation include the type of cancer, type of treatment, whether there are co-morbidities and toxicities, the stage at diagnosis, whether the cancer is resectable, and the progressive and disabling functional impact of the disease. A combination of these factors need to be matched to the type of occupation of the patient.

As noted in testimony last December by Commissioner Astrue, there are certain cases where there is over 90% certainty that the individual would be eligible for benefits, and these cases are fast-tracked through the SSA's Quick Disability Determination System. I believe that some cancer diagnoses do and should qualify under this category, given that they have a discouragingly low 5-year survival rate after diagnosis, less than 15%. Examples include cancers of the lung, pancreas, liver and esophagus. In addition, any metastatic cancer arising from the lung, pancreas, colon, stomach or liver may be associated with a survival rate of less than one year.

There are other cancers and treatments where the short and long term side effects vary according to the type and duration of treatment. Some of the newer targeted therapies may have minimal side effects, for example gleevac for CLL, whereas the treatments of high dose chemotherapy with bone marrow transplant may result in severe and long-term side effects. These treatments can also cause serious toxicities of other organ systems that may not be totally reversible.

There are other consequences of cancer and its treatment that can cause serious functional impairment. One well recognized tool is the Karnofsky scale, which has been used for decades to measure patient function for patients not undergoing active treatment. On a 10-point scale from 0-100, generally those patients with a score of 70 or less are not able to work, have a range of symptoms, and carry out normal activities only with significant effort.

I had been asked to address whether biomarkers or other diagnostic tests had progressed to the point that it can be used as part of the eligibility determination process. By way of

background, biomarkers are substances found in blood, body fluids or other tissue that show the risk or presence of disease before cancer has had the opportunity to progress in the body. They can be used to detect disease at an early stage, as evidence for patient specific efficacy and toxicity, or as tools for the development of new drugs and therapies. In 2000, the National Cancer Institute launched the Early Detection and Research network to identify and develop biomarkers. Unfortunately, at this time, most biomarkers have not advanced beyond the discovery phase and the number of biomarkers validated for use in drug development or qualified for clinical applications is still very small.

Case Examples. I contacted the Director of Social Work at Dana-Farber to gain more direct input as to the importance of this proposed initiative. The Director, in turn, sent an email to the social work staff asking for any case examples. The response I received is that there are countless stories of how the compassionate allowance would have helped our patients. One social worker said that she has recently seen four patients in their 30s and 40s who died within a year of diagnosis. She added that for “most patients it takes a couple of months before they can even get their heads around the need to apply (understandably).” Another social worker said, “This happens ALL the time. Patients that try to ‘do the right thing’ and continue to work are penalized. Hope this helps.”

The social workers told me of two recent cases. One was a 38-year-old patient with advanced gastric cancer. He applied for SSDI, lived on savings, his family helped and then four months into the application was notified by SSDI that he was being "audited" and that the application would take even longer. He was the breadwinner and had three kids under age eight. His application finally moved along but he died within a year of diagnosis.

Another recent case was a 57-year-old man with advanced esophageal cancer. According to our staff, he was very hard working, a devoted father, husband and Vietnam veteran. He worked as a maintenance man in an elderly housing complex. Despite his advanced cancer, he continued to work because there were no other options. His wife collected the paperwork for SSDI benefits when his decline began. When contacted by the social worker regarding sharing this case example for this testimony, the patient's wife said to the social worker, “I’m almost embarrassed to say that we did not even apply in the end

because we knew it would take too long. He declined so fast as you know”. In both of these cases, the compassionate allowance would have made a real difference.

SSA Disability Review Process. Given the difficulty in creating a paradigm that will be appropriate for all the varied cancer diagnoses, the input and judgment from clinical oncologists or other treating physicians (surgeons, etc.) will allow the SSA staff to better determine eligibility. As previously, the outcome cannot be predicted with absolute certainty. The field of cancer medicine is changing rapidly, and these assessments are based on probabilities.

One approach may be to solicit input from a clinical oncologist early in the determination process, and set this up in the form of a contingency. This way, the clinical oncologist could provide the necessary documentation, and a disability determination could be made but not activated. This would allow the patient to continue working as long as he or she was able, and the patient would know that the benefit could be activated quickly if their condition deteriorated. Further, SSA staff could consult with clinical oncologists who would serve as experts in evaluating the application in those cases that require a hearing or where SSA was considering denying an application.

Conclusion. Despite the improved survival rates for persons diagnosed with cancer, there are many patients who die within a year or two or who are disabled for extended periods of time. We believe there are objective, evidence-based medical criteria that can be developed, based on type of cancer, stage, co-morbidities, and functional status that, in combination, can assist SSA in making accelerated determinations. We at Dana-Farber would be pleased to identify some of our faculty and staff - researchers, clinicians, administrators, and biostatisticians – to support this effort. The compassionate allowance will assist countless cancer patients and their families at a time when they are dealing with serious medical and functional impairments as well as struggling with financial issues due to medical debt and loss of income.

Thank you for giving me this opportunity to participate in this public hearing.